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Life After Death: An Occupational Therapy Perspective on Supporting Hospice Caregivers in the Transition out of the Caregiver Role

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BACKGROUND

There is an estimated two million people who are as caregivers for individuals at the end-of-life stage, the majority of whom are unpaid family caregivers (Ornstein et al., 2017). Family caregivers of hospice patients experience a myriad of stressors and psychosocial challenges that impact their health, well-being, and quality of life (Rakes & Washington, 2015). The role of occupational therapists in supporting family caregivers specific to hospice needs to be explored, described and advocated for.

PURPOSE

To evaluate the occupational impact of transitioning out of the hospice caregiver role in order to assess and advocate for occupational therapy’s role, during and after hospice services.

METHODS

- A total of 10 participants were recruited from Facebook groups (6), online caregiver forums (2), and snowball sampling (2).
- The former family hospice caregivers each participated in 45-minute in-depth interviews.
- Interviews were transcribed, coded, and analyzed thematically using the software Dedoose, for organization.



RESULTS

THEMES	
Quality of Support Systems	
<ul style="list-style-type: none">• Family, friends & community• Hospice & Professional Bereavement Care• Online Support Groups	<ul style="list-style-type: none">• “My biggest support has been my husband. He was there every step of the way.”• “And I really didn't feel the loss of [my husband] because I had friends and neighbors who were always checking in on me.”• “I really didn't want to get that personal in a group setting, so I did one on one with our social worker and bereavement counselor.”
Social & Cultural Influences	
<ul style="list-style-type: none">• Contexts & Environment• Other Roles & Responsibilities• Norms & Expectations	<ul style="list-style-type: none">• “...here in America, grieving seems like it's not allowed. It's not acceptable. OK, the funeral and then it's back to business as usual”• “Well, life was really busy right after she died...it was like a whirlwind of life events.”
Spiritual & Religious Influences	
<ul style="list-style-type: none">• Beliefs & Values• Relationship to Death• Belonging & Community	<ul style="list-style-type: none">• “Because of the faith that we have... we've never feared death or... the separation”• “I feel like I am close to them through this altar.”
Occupations that Connect them to Loved One	
<ul style="list-style-type: none">• Continuity of caregiving experience• Support other caregivers• Prior & New Occupations	<ul style="list-style-type: none">• “It's almost an obsession to create something after someone dies.”• “I feel better when I help other people...I want to inspire other people, that you can survive and thrive”• “When I'm on his sailboat... his presence is very strong there”
Personal Projects & Goals	
<ul style="list-style-type: none">• Freedom & Time for Goals, Dreams, Roles & Activities on the “Backburner”	<ul style="list-style-type: none">• “There were a lot of personal projects that I needed to do for myself”• “I think [it] was something I always wanted to do but I never thought I would have the time to do 'cause... caregiving consumes your life.”
Restorative Occupations	
<ul style="list-style-type: none">• Meditation• Sleep• Health Promoting Occupations	<ul style="list-style-type: none">• “Right after Hospice, my goal was to get back to the gym and start cooking in a healthier way”• “I established a beautiful new routine. I'm always up like pre-dawn or right at sunrise...I do a heart meditation”

The occupational impact of losing the caregiver role can be correlated to:

- Be dependent on the Quality of and Access to their Support System
- Influenced by client factors, including Social and Cultural & Spiritual and Religious contexts
- Positively impact health outcomes through participation in occupations that Connect them to their Loved One and the Caregiving Experience, Personal Projects & Restorative Occupations

DISCUSSION

This phenomenological study aimed to assess supports and needs of former family hospice caregivers and the occupational impacts of caregiving to determine occupational therapy’s role. The determined supports and needs are unique to individuals of different cultures, life roles, caregiver identity and relationship to the care-receiver. While grieving and loss are subjective experiences, it can be inferred that with adequate support, as perceived by the caregiver, positive health outcomes and quality of life are achieved.

DISSEMINATION

lifeafterdeathot.com

- Pre-Bereavement & Bereavement Self-Guided Program and Resources for caregivers and bereavement providers
- Advocacy for OT’s role in hospice and bereavement for professionals and students.

IMPLICATION FOR OT

- Support or enhance bereavement outcomes through consult
- Apply intervention aimed at identifying support systems and intrinsic values placed on participation in meaningful and purposeful occupations, roles, and routines to improve health and wellness.

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REFERENCES:

